

Privacy notice for project: The ExacQual Study

I have questions or want further information. Who do I talk to?

If you have any questions or concerns about how your data will be processed within this project please contact Hull Health Trials Unit (HHTU) in the first instance:

Email: hhtuenquiries@hyms.ac.uk

Telephone: 01482 463444

Address: 3rd Floor, Allam Medical Building, University of Hull, Hull, HU6 7RX

If you would like further information, please contact the University of Hull, Data Protection Officer (DPO):

Email: dataprotection@hull.ac.uk

Telephone: 01482 466594

Address: University of Hull, Cottingham Road, Hull HU6 7RX

What is this project about?

Chronic obstructive pulmonary disease (COPD) is a common lung disease which causes sufferers to experience breathlessness. People with COPD often suffer episodes where their symptoms worsen over a short period of time, termed exacerbations of COPD, which often required treatment with medication and are a common reason for emergency department attendance and hospital admission. People who suffer frequent exacerbations tend to have a worse quality of life, deteriorate faster over time and are at higher risk of dying. Previous research suggests that people with COPD do not always seek medical help during exacerbations.

We aim to improve our understanding of how people with COPD and the people who care for them feel about exacerbations, including their experiences, expectations and understanding of these events. We would like to understand what differences there may be between people who have frequent exacerbations requiring medical help and those who have exacerbations for which they don't seek medical help. We will ask about how the COVID-19 pandemic has affected their experience of exacerbations and response to symptom worsening events.

Eligible patients with COPD and their carers will be invited to participate in semi-structured qualitative interviews. Groups will be established between patients who are i) prone to moderate and/or server exacerbations (Group A) or ii) not prone to moderate or server COPD exacerbations (Group B). The above groups will be analysed separately with commonalities and differences identified.

How will you look after your information and have access to it?

If you agree to take part in the trial, the University of Hull will keep your name, contact details and age confidential. The University of Hull will use this information as needed, to contact you about the research study interviews you have agreed to be part of and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Your data will be managed and stored by the Hull Health Trials Unit (HHTU) using their data capture system REDCap cloud and BOX Governance file storage system. Both systems have high levels of security and all data is stored within the EU. Only staff working on this study will have access to your data. Staff have individual logins and all activity is logged. The HHTU hold a Data Security and Protection Toolkit (DSPT) which provides assurance that they are practising good data security and that personal data is handled correctly. More information about the DSPT can be found [here](#).

How long will you keep it?

The University of Hull will keep identifiable information about you by retaining the consent forms until 5 years after closure of the research project.

What is the purpose of the General Data Protection Regulations (GDPR 2018)?

Under the GDPR 2018, there is a legal basis for processing personal data we collect about you during research as this is being done in the public interest (schedule 6) and for scientific research purposes (schedule 9).

Whilst the study is commercially sponsored by AstraZeneca, they will not receive any personal database about you. The University of Hull is the data controller of the information it collects and processes as described in this Notice. This means that it has the core legal responsibility to safeguard the information and ensure it is processed lawfully. The law is set out in the EU General Data Protection Regulation (called “GDPR”) and a new UK law, the Data Protection Act 2018. In particular UOH must:

- Take steps to ensure that the data it processes is accurate and up to date;
- Give you clear information about its processing of your data, in one or more privacy notices like this one and the participant information sheet (referred to together in this section as a “Privacy Notice”);
- Only process your data for specific purposes described to you in a Privacy Notice, and only share your data with third parties as provided for in a Privacy Notice; and
- Keep your data secure.

The law states that we can only process your personal data if the processing meets one of the conditions of processing in Article 6 GDPR. As we are processing your special category data we also must meet one of the conditions in Article 9 GDPR. Special Category data includes personal data which relates to your ethnicity, sex life or sexual orientation, health or disability, biometric or genetic data, religious or philosophical beliefs, political opinions or trade union membership. Under the data

protection legislation we need to explain the legal basis for holding your data, i.e. which of these conditions apply.

For our research project the following conditions apply:

- Article 6.1(e) of the GDPR, i.e. our processing is necessary for the performance of a task carried out in the public interest. Research is a task that UoH performs in the public interest, as part of our core function as a university;
- Article 9.2(j) of the GDPR, i.e. our processing is necessary for research purposes or statistical purposes. This condition applies as long as we are applying appropriate protections to keep your data secure and safeguard your interests.

Your rights as a data subject

Under the data protection laws you have a number of rights in relation to the processing of your data. These are limited by the lawful basis under which we hold your data. Your rights are:

- Right to request access to your data as processed by UoH and information about that processing
- Right to rectify any inaccuracies in your data
- Right to place restrictions on our processing of your data

If you would like to exercise any of your rights as outlined above, you can contact the DPO as above or visit the Data Protection page on our website

<https://www.hull.ac.uk/choose-hull/university-and-region/key-documents/data-protection.aspx>

We will always aim to respond clearly and fully to any concerns you have about our processing and requests to exercise the rights set out above. However, as a data subject, if you have concerns about our data processing or consider that we have failed to comply with the data protection legislation, then you have the right to lodge a complaint with the data protection regulator, the Information Commissioner:

Online reporting: <https://ico.org.uk/concerns/>

Email: casework@ico.org.uk

Tel: 0303 123 1113

Post: Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF